

**Episode 122 - Bonnie Fader Wilkenfeld, Dr. Kenneth Robey, and Eileen Murray: Impact of the Arts on Identity Structures of Individuals with Developmental Disabilities**

[00:00:08] Welcome to in social work. The podcast series of the University at Buffalo School of Social Work at [www.insocialwork.org](http://www.insocialwork.org). We're glad you could join us today. The purpose of social work is to engage practitioners and researchers and lifelong learning and to promote research to practice and practice to research. We're so sure we cram a lot into our warm weather season here in Buffalo our downtown waterfront is hopping. You can attend a concert at a microbrewery rent a kayak and get out on the lake. Well maybe not in that order. And then proceed to the Elmwood Village or just about any kind of experience. I'm Peter Sobota quality of life is a subjective concept embedded in an individual person's experiences and self-determination and self-expression are important pieces of a person's quality of life. In this episode our guest Bonnie Wilkenfeld Kenneth Robey and Eileen Murray discuss their study of the quality of life of persons with developmental disabilities whose ability to engage in self actualizing and fulfilling experiences is often limited sometimes even ignored by their significant others and caregivers. Our guests discuss their work examining the link between a facilitated arts program and the participants sense of self. They describe just what is a facilitated arts program. The process for the artist mentors who incidentally are professional artists and the process of the artist's creation they discuss their findings as they examine the impact of this collaboration. Our guests described the broader applications of their findings beyond persons with developmental disabilities.

[00:02:04] Future Directions for their work and the implications for social work practice Bonnie Wilkenfeld LCSW is a doctoral candidate at the Rutgers University School of Social Work. Kenneth Robey Ph.D. is director of the Maithili institute for research in developmental disability at the Athenian medical and educational center. And Eileen Murray is the program director at the Mithila arts access. Our guests today were interviewed by our own John Kessler a doctoral candidate here at the UB School of Social Work. My name is John Kessler and I am with the School of Social Work at the University of Buffalo and today I'm speaking with Bonnie Wilkenfeld and her colleagues Dr. Ken Roby and Eileen Murray at the Metheny Medical Center. Thank you and welcome to all of you. Thank you. Thank you. Thank you. So if we could start can you describe the project briefly in terms of your aims and goals. Sure. This is Bonnie. First of all in order to be able to fully describe and appreciate the project we must really give you a good understanding of the population that we serve. Latini medical and educational center is a specialized school and hospital that serves children and adults with multiple developmental disabilities. The people that are served by her facility are not here only because of their developmental disabilities but rather because of medical complexity and they're relatively fragile health status. Our primary patients have generally between 10 and 15 diagnoses in addition to their primary diagnosis. Most of our persons serve need assistance with all aspects of activities of daily living. They may not be able to verbally articulate and the do rely on assistive technology different types of assistive technology for a variety of purposes including mobility and communication.

[00:03:57] So in terms of autonomy and self direction there are many barriers that they may experience. This project was inspired by this population and it's partly an evaluation of a program that I lead as the director of the facilitated arts program called Arts Access which is part of an array of services that we provided our medical center and the primary goal of that program is to enrich each individual's sense of self by increasing self-esteem. Achieving a sense of self sufficiency and providing an avenue of creative self-expression for our purposes we're viewing self perceptions and identity as a dynamic unfolding process which is impacted by the multiplicity of different roles at

locations applications affiliations albeit the various social context which comprise individuals life. In my particular thesis is that by exposing individuals to which and are social contextual environments ultimately their sense of self their identity complexity will be affected and become more complex and nuanced. And so we're suggesting that participation in facilitated arts program such as arts access might serve as an example of such an enriching type of environment. Very good Portadown speak to the actual present and problem you are looking to address.

[00:05:21] Sure we are exploring the impact of participation in the facilitated arts program and the like quality of individuals with developmental disability and suggests that that's one particular type of stimulating enriching social environmental context as I previously mentioned and we're also exploring the utility of hierarchical classification analysis also dubbed high class or short as a tool for depicting such self perception as we did do some pilot work a year ago utilizing a high class analysis and findings suggested positive self perceptions were associated with the various art identities and in keeping with the social model of disability framework we've adopted a destructive stick viewpoint in that by exposure to enriched environmental contexts such as provided by an Arts Access Program. There may be an impact on identity complexity and subsequently in locations were improved life quality for the individual. Can you please describe what exactly the facilitative art process looks like. Yes this is Xylene and I'd be glad to do that as Bonnie described earlier. The Heaney's population have many physical limitations. Most are in wheelchairs and have limited mobility and many are non-verbal so as such. Many don't have the physical means by which to grasp the paintbrush let alone will live to their satisfaction. And they don't have the physical ability to write or type a novel or a poem or to choreograph a dance or to direct to play. All that being said they do have the creative ability. So our program provides freedom to realize their artistic visions and that's essentially our mission and our officially stated One is the mission of arts access is to provide individuals with disabilities the freedom to create in the visual literary and performing arts. Now the key words there are provide the freedom. So in order to Vereide this freedom we facilitate the process and the most basic of terms. We serve as the arms and the legs for people who can't use theirs and in doing so we need to find out exactly what they want to do and the art medium of their choice. Painting choreography writing drama sculpture. And for many of our participants all of them essentially the siltation equals communication.

[00:08:02] We have created a unique methodology combined of questioning visual charts and systems and that puts every single choice into the hands of the artists with disabilities so the people who stayed are aptly called facilitators. They're working professional artists and they serve solely as a conduit between the client Metheny client and their artwork. And it's that the Souldiers job and the most important part of their job is to carry out those choices to the exacting and degree that nothing is done. No is put on the canvas. Step happens within the dance until the facilitator is 100 percent sure that they're carrying out that individual's creative wishes. Sounds like it definitely could be a little bit of a challenge for staff at times. Yes. You hit the nail on the head. The people that we hire are all professional artists in their field and we always say that all facilitators are professional artists not all professional artists can be a facilitator. It really requires a specific type of person. Abundant endless patience and the ability to remain completely neutral in the art making process. So the people that we have on staff here are extraordinary in their ability to do that and they go through a stringent extensive training process to learn the systems the methodology the questioning methods cetera. Okay. Can we go back for a second to the methodology that was used this high class program. Can you speak to that about. Yes this is Ken WEAFF and using a research methodology that comes out of the personality and social psychology research of schema Rosenberg and Mike Garah and others the various times been affiliated with the psychology of a permanent record University.

[00:10:10] The general idea that guides this methodology is that one's sense of self is actually a collection or an amalgam of more specific interrelated selves. And about said Algy is one in which

we gather large amounts of stuff report data from individuals regarding these various selves or identities that at once identities are derived from many different sources and many different contexts. They are derived from the individual's family relationships. Like myself as a son or myself as a cousin Joe or they could be derived from occupations or hobbies like myself as a teacher myself as a volunteer nursing home myself as an artist or they could be derived from one's friendships myself as a friend to Lisa or that it could come from one's religious affiliation group memberships physical characteristics health conditions etc.. The goal here is get from the individual a representative inventory of these different sorts of identity. Then once we have that inventory of identity we gather a vocabulary of what we call features. These are the words and short phrases that the individual uses to describe herself and enacting the various identities. For example when I'm an artist I might feel free excited expressing myself and at times I might feel sad or frustrated and when I'm acting a different identity perhaps that of a student I might experience myself as having some of the same features but others as well. So this process is one of gathering identities and then to term in the descriptive words and phrases are what we call features that the individual might use to describe herself and each of those identities. The result is a matrix of identities by features.

[00:12:09] If you can imagine a matrix where the identities are listed across the top and the features listed along the side with the body of the matrix filled with ones and zeros indicating whether or not the individual attributes a particular feature to any particular identity. Then we get to the fun part or at least I think it's fun. We can then take that matrix of ones and zeros and toss it into really wonderful statistical that was developed by Paul Bulc who's a researcher in Belgium and Seymour Rosenberg at Rutgers the algorithm as you said is called high class high class is an acronym for hierarchical classes analysis. It's a clustering algorithm that in some respects similar to the hierarchical clustering procedure that you might find in SPSS or the other common statistical packages but it has the advantage of hierarchical clustering and organizing both sides of that matrix not only the identities but it clusters and organizes the features as well. So both sides of that matrix get organized in a hierarchical fashion. It organizes the identities based on their sharing of features and it organizes the features based on their code occurrence. Among the is the output that an algorithm gives us what we need to construct what is basically a very rich graphical depiction of the interrelationships among someone's identities and among the features as well. In effect it is a map of the individual's sense of self.

[00:13:49] Now with that map with that graphical depiction by looking at things like the number and the content of different clusters that are formed by the analysis were able to look at things like how complex ones overall sense of self is and we can look at indices that suggest the subjective importance of any particular identity within that broader map within a broader sense of who the individual is. So when we're using this technique to look at identity and people were participating in the arts for example we can get a sense of how prominent the arts are as a source of identity for the individual. How central the arts are to that person's sense of self and at a qualitative level we can get a real good sense of what kinds of features what kinds of soft descriptors the individual associates with his or her being an artist. If any of our listeners are so inclined they might want to use their favorite search engine to search the words high class. If I see Las just one as an identity and they'll come up with a number of articles. Some of them will be open access articles that have simplified or abbreviated high class depictions so they can get a better feel for what we're talking about here. And we at Mazzini have a number of publications that are specific to support class with persons who have disabilities. And you might find those in the disability literature or in the psychology literature. I don't believe that any of those are open access at this point but if anyone would like to get in touch with us here at Masini we'd be glad to get the references to you. You've certainly touched on some key points and some critical aspects of it but I'm wondering if there's any other specifics or unique aspects related to these analyses that you'd like to mention.

[00:15:37] Yeah I think the most unique and interesting thing about this process of mapping an

individual sense of self is that it helps us look at identity in persons with disabilities or anyone for that matter in a way that gives us both ends of the qualitative and quantitative spectrum. We get fantastically colorful qualitative information about the individual showing us a wonderful snapshot of how the individual experiences any one of their specific identities or cluster of identities. But it also gives us a bunch of things that can be looked at quantitatively across individuals and even between groups we can compare structural aspects of identity like overall complexity of one's sense of self between groups based on disability status based on individuals living situations or really any of a range of variables. So do you see any benefits to participating in this process. Well this is Bonnie again and I can tell you after doing several of these a sequence of interviews with people at the facility here they generally seem to find it very fun and enlightening to go around. More specifically that the structural map that arises from the algorithm becomes an actual visual representation where they can see how their roles and attributes interact amongst each other and so it's really enlightening the individual and gives them a lot of self information and it's really well suited methodology or a population who had issues with articulation in speech the responses that are elicited from the respondents are typically short phrases and adjectives describing themselves when in acting certain scientists. It also as Ken alluded to will list its graphic self reflection. Oftentimes a very poetic individualistic way can you provide some examples of how self perceptions may be depicted. Well what we've been finding is that every structure that arises from these individuals completing this process is distinct and unique.

[00:17:43] The self perceptions that are displayed in a very individualized identity structural math and in reviewing several of these high class analyses with people who are participating in the Arts Access program it was striking to us how those art personified if you will seemed to rise high in the structural hierarchy and are invariably associated with positive attribute. So the fact that they rise high in the structure suggests to us that this has prominence for the individual and the fact that they are associated with positive attributes or features may have implications for their perceptions of life quality in these individuals. Eileen can provide a wonderful illustration of how one artist articulated her life experience which beautifully became reflected in her structural math. I'm going to ask Eileen to share that with me now. Sure. Thanks Bonnie. This particular artist created multi disciplinary performance piece which in itself was an artistic masterpiece of self-expression and epic same time the content expressed the different identities that she felt she had within her. So she first created a written dramatic piece called for people one body. And from there she choreographed a dance to accompany it. She chose actors for the voice over And directed each one she designed the costumes and the makeup chose the music and also had one of her paintings titled Hello projected behind the performance and I actually like to quote directly from her original script because it really is more powerful than my description could ever be. So this is right from that and she starts out I have four people who live inside me. One person is strong the other week one person is sexy the other one's crazy. They have names. Natalia is the star.

[00:19:53] Crystal is the strong one. Nicole is the sexy one and some vamp is the crazy one. The strong one uses the weak ones experiences as material for her art. She uses art like medicine to heal the others. We don't like pills for some reason Natalya tried painting. She'd found it helped with her anger and depression. Hell was painted during this period. Nicole loves sex. Nicole is a bad girl according to Natalia. Crystal doesn't think Nicole is bad. Natalia is more conservative while star Crystal is a free spirited artists now. Vamp pushes Nicole to do things that an Italian wouldn't approve of. Sometimes she gets star Crystal to try new things in the arts. It's sort of like sisters fighting over a car. We know what days we get. Nicole is the substitute when any of the others wants a break. Sometimes we have M.S. It's worse for everybody. When the body is in pain snuff vamp takes over because she enjoys pain. We want people to understand us and when I tell you that this piece was moving funny poignant insightful to view. That doesn't even begin to do it justice. It really sounds like a tremendous example of self-expression but also how not only the individual but staff can benefit from the engagement. Absolutely true. And not only staff this piece was performed

at a yearly event that we do here in Arts Access called Full Circle and it's a multidisciplinary event displaying the visual art. And then there's also a stage show which incorporates the dramatic the dance and all of the arts into this cohesive piece.

[00:21:55] And for people one body was performed a full circle to an audience I would say of 250 to 300 people and people came up to me afterwards and they said that was life changing for me. So it really goes far towards educating and enlightening the public as to what people with disabilities can do. And so we've gotten one scenario of what it's perhaps like for one individual. But in general what is the experience like for the Arts Access participants. Well this is Bonnie again speaking and I'd like to share that from what we've been able to glean the approach is an opportunity for self-expression that they might not be exposed to in more conventional forms of art or recreational programs. One particular respondent articulated in an extremely nuanced way saying that being involved in this process put her in a free minded world and just being able to elicit that kind of expression has not been able to be obtained through other types of interview formats. Another aspect from the program can be best articulated through hearing some quotes from actual participants. If I can share some of those with you I think they could. As Eileen indicated much more clearly describe the experience from their perspectives. They basically included expressions of being in control and allowing themselves to fully express themselves. Here's some quotes I am free because I have the only say in what happens in my art. It relaxes me and allows me to get my frustrations out I can express myself any way I want through my art. Unlike the rest of my cell which is so controlled I have constructed a world of color an idea that is unique to my individuality.

[00:23:48] I have a great deal of accomplishment knowing that this painting would not exist if it weren't for my idea and freedom to explore and perhaps the most powerful board I have in my sample here as every stroke every word every dance step is ours. Yes you're our hands but arts access is so much higher than even our survival. It's being able to let our emotions have a quiet place to run a sanctuary. And in terms of an aspect from the high class depiction of the pilot data we did mention that invariably the arts access personnel were affiliated or associated if you will with a positive self perceptions. So this implies to us that being part of this arts program is an enriching experience and perhaps enhances the life quality for these individuals. Certainly quality of life is a critical issue when it comes to this population and it also sounds like the Arts Access Program removes some of the barriers that prevents inequality quality of law. Exactly I mean that is a key component of a conceptual model framework if you will that we're working from whereby and I'll talk about this when we get a little further into the interview about the social justice implications in terms of breaking down those barriers. But we do feel that this Arts Access Program serves as an excellent illustration of one type of complex contextual social environment that by participation provides our participants with the ability to become producers and contribute to society which is so enhancing to their self perceptions and yet then feeds back onto societal perceptions. In looking at our population as contributors as opposed to just consumers. So it has that component as well.

[00:25:48] And it seems like this program certainly has the potential to benefit this population of individuals in multiple ways. But other populations that might benefit from this approach as well. Yeah this is Bonnie again in our arts access team has been requested to provide trainings in various other venues. Irene and her team have provided trainings to other developmental centers out of state. We're in negotiations now with veterans hospitals and talking with we're dealing with various trauma related types of issues. There's perhaps a venue available in rehab facilities for people recovering from different types of physical trauma perhaps paralysis Alzheimers patients and others patients with different types of dementia. Mental health populations in terms of depression psychosis perhaps even with different autism spectrum disorders and certainly with elderly. This is I mean and I just want to add in there we've actually and thank you Bonnie. Really covered the spread of populations that we can reach and are planning to region are currently reaching. Specifically we're currently reaching people with autism on all ranges of the spectrum. We have

two successful satellite programs that are operating in New Jersey and all of those folks are on the autism spectrum. And it was really gratifying to us when we first did this to find out that that facilitated our process works with population very different from those at Makini. But it does work and what we do is we adapt the process not only to the type of disability that that person has but to each individual. So it's really exciting to think about the different people that could benefit from this process. Definitely.

[00:27:49] So where do you see your team going next. What do you see as future direction for this project. Well this is Bonnie again and without a doubt empirical research needs to be done in a variety of different contexts. I mean we have a very specific population that we work with and certainly the implications are to bring this out into other venues research needs to be done and to see the effectiveness of those differences with the responses that other populations might have to this approach. Currently my dissertation research is a mixed method's approach and I'm looking at the difference in identity complexity between our access participants and nonparticipants and utilizing this high class methodology and I'm triangulating that with a qualitative interviews in order to strengthen the credibility and the rigor of the analyses. But as far as implications for social work education practice in thinking about this from a macro perspective policy and social justice implications as I mentioned before in terms of breaking down barriers as you mentioned John by providing access to such facilitated arts programs may underscore a path for individuals with severe and complex medical and physical disabilities to assume the more productive roles in society thereby gaining higher social image which may help to break down misperceptions stereotypes negative societal reactions and open up policy decisions to provide greater access to creating stimulating social recreational educational vocational environments for the population.

[00:29:29] So that's looking at it from a more macro policy perspective and then from the micro perspective in terms of the role enhancement the ability to provide a venue for self-expression and self-determination as those quotes and examples that Eileen alluded to very vividly portray certainly seems to have life enhancing aspects to this and the other aspect that I do want to mention is that we do want to focus on the high class analysis perhaps its potential as a tool for diagnosis and assessment. These structural representations that develop out of the algorithm are really striking and they are so helpful in having this visual depiction to work with clients with and show them how their different roles that they interact with each other and what seems to be the most important and positive value because we do see the positive and the negative attributes as they are associated with the various roles could also provide perhaps information for clinicians in terms of resilience in building up resistance to trauma and loss. There may be that aspect to it as well. Potential. I really think that this is a tool methodology if you will that has a future ahead of it in social work practice. It sounds that certainly has quite a bit of potential and certainly has a more creative approach to helping individuals to be successful and can have considerable potential to carry over into other aspects of their life. Whether or not they are in a residential facility or work with a clinician etc.. One thing I did neglect to mention that I really think is important as well is that the arts access facilitated communication techniques that they use their methodology which Eileen described before in terms of the very specific involved process where the choice making options are broken down in a very specific manner can really perhaps provide a wonderful opportunity for training in terms of caregivers and family and other individuals that would be interacting with a population to express their needs and understand what they want in terms of self determination factors.

[00:31:51] So I didn't want to mention that as well. Veriga. Are there any other concluding remarks before we and our podcast today. I really appreciate my University of Buffalo's interest in our project here and allowing us the opportunity to share this with you and do this podcast. I really appreciate it. Thank you so much. This is I mean and I'd like to thank you all so I truly appreciate it. And from an artist and an arts access perspective it's really so exciting for us to have what we do here. Brought into an evidence base forum if you will. The arts are so hard to measure as we all

know. And so for there to be a way to measure the impact on the people that participate in arts access is really invaluable. And so I'm so glad that Bonnie has chosen arts access to focus her thesis on and for Cannes participation. Also of course and I'll chime in. John thank you very much and thank you to the university as well. You're welcome. And thank you for joining us today. You've been listening to Bonnie Wilkenfeld Kenneth Robey and Eileen Murray discuss the impact of the Arts on identity structures of individuals with developmental disabilities on social work. Hi I'm Nancy Smyth professor and dean of the University at Buffalo School of Social Work. Thanks for listening to our podcast. We look forward to your continued support of the series. For more information about who we are as a school our history our programs and what we do we invite you to visit our Web site at [www.socialwork.buffalo.edu](http://www.socialwork.buffalo.edu).